

The Family Caregiver's Journey: No Map, No Plan, No Guide

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Who are the Travelers?

"The chronically ill often are like those trapped at a frontier, confused in a poorly known border area, waiting desperately to return to their native land...This image should also alert us to...the relatives and friends who press their faces against windows to wave a sad goodbye, who carry sometimes the heaviest baggage, who sit in the same waiting rooms, and who even travel through the same land of limbo, experiencing similar worry, hurt, uncertainty, and loss...."

Arthur Kleinman, *The Illness Narratives* (New York: Basic Books, 1998), p. 183.

Who are the Caregivers? What's Changing?

- ☐ More men are caregivers, especially at younger ages
 - ☐ But women still provide most heavy-duty care
 - ☐ Children and young adults are caregivers too
 - ☐ New group of caregivers—parents and spouses of young adults injured in wartime
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Who are the Caregivers? What's Changing?

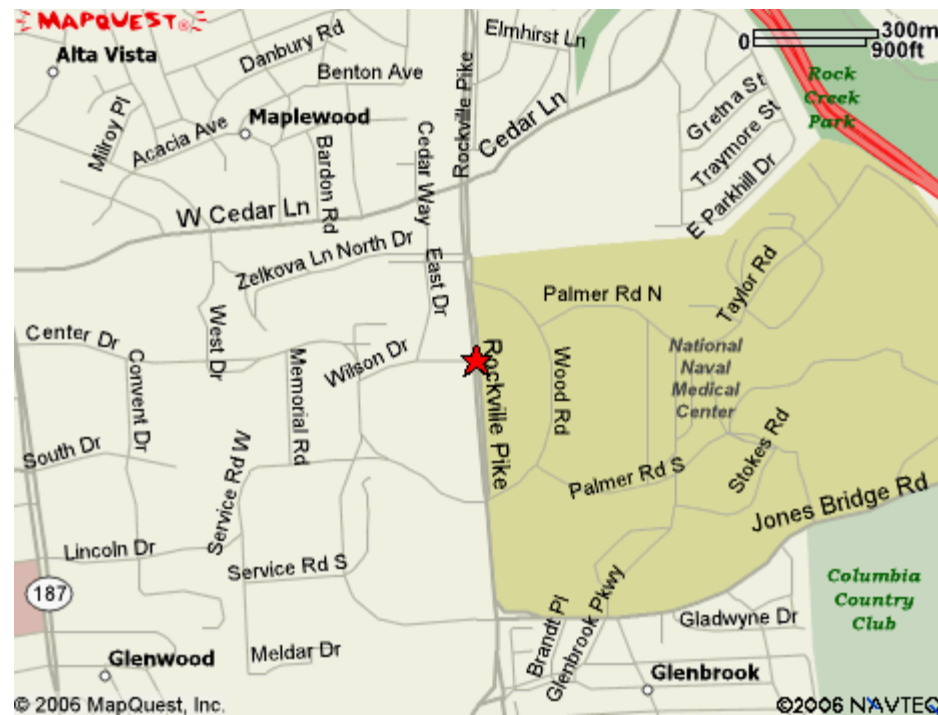
- ❑ **NLTCS: Between 1994 and 1999, number of spouses and children providing care to an older person with disabilities increased, while the use of any formal care by these individuals declined.**
 - ❑ **In 1999 a larger proportion of caregivers were caring for persons with higher levels of disability.**
 - ❑ **About 30% of children with a parent in assisted living were providing care.**
 - ❑ **Bottom line: Family caregivers continue to provide vast majority of long-term care for people with disabilities.**

 - ❑ **Source: AARP Public Policy Institute, January 2006.**
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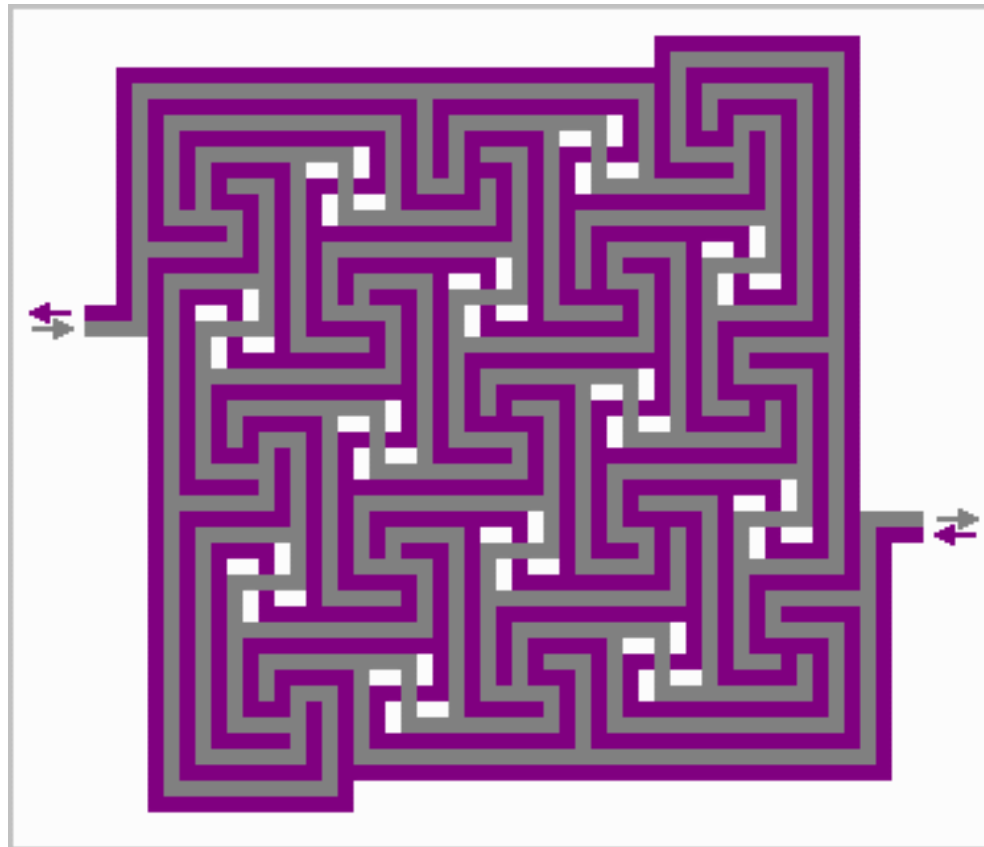
HIPAA: A Roadblock on the Journey

- ☐ **Intended to protect patient medical information from unauthorized use, HIPAA is being used as a barrier to communication with families.**
 - ☐ **Law never intended this to happen, and GAO report and CMS guidance specifically reject this interpretation.**
 - ☐ **We need re-education of all staff on appropriate use of HIPAA.**
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One type of guide on a journey....



A journey through the health care system



Transitions on a journey

Even if you know the destination and have a map, sometimes you need to

- ☐ Get off the highway
 - ☐ Stop and ask for directions
 - ☐ Decide whether to go ahead, go back, or change direction.
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Transitions in Caregiving

Points at which significant adjustments or alterations must be made in the caregiving situation because of changes in the:

- ☐ **care recipient's condition (trauma or slower deterioration)**
 - ☐ **caregiver's ability to care (illness or burnout)**
 - ☐ **family's situation (other illnesses, births, deaths, moves, jobs)**
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Caregiving Transitions and the Health Care System

These changes often lead to changes in care setting or organization:

- ☐ Hospital stay (admission and discharge)
 - ☐ Diagnosis leading to new set of physicians and medications
 - ☐ Short-term nursing home or rehab facility stay (admission and discharge)
 - ☐ Assisted living or other facility
 - ☐ Long-term nursing home placement
 - ☐ Paid home health care (case opening and closing)
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Caregiving Transitions and the Health Care System

Each transition is a challenge....

Anxiety, stress, worry for the caregiver and care recipient in an alien environment

And an opportunity...

For health care and social service professionals to provide assistance through the transition and beyond.

What Caregivers Say about Transitions from Hospital to Home

Series of United Hospital Fund focus groups with experienced caregivers and national/New York City survey

- ❑ “I wasn’t prepared.” Caregivers feel poorly equipped to handle both the technical and emotional aspects of the changes in care.
 - ❑ Survey showed lack of training on equipment, bandages and wound care, and ADLs
 - ❑ Medication management had highest rate of instruction but still not universal
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Family Caregiving Grant Initiative: Seven Hospital-Based Programs

- ❑ \$2.1 million United Hospital Fund grantmaking initiative 1998-2002; lessons learned include:
 - ❑ Family caregiver advisers are the community's "key informants" and should be an integral part of program planning, development, implementation, and evaluation.
 - ❑ In a "culture of care," family caregivers are acknowledged as the experts about patients, while professionals are experts about disease.
 - ❑ Formal staff education should be combined with informal contacts.
 - ❑ An effective way to reach staff is through their concerns about their own relatives.
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“This Case Is Closed: How Family Caregivers Manage when Formal Home Care Ends”

- ❑ Study of caregivers of stroke and brain injury patients, who face long period of recovery and who have significant physical, psychological, and cognitive problems**
 - ❑ Collaboration with three Home Health Care Agencies (CHHAs)**
 - ❑ Steven Albert, Ph.D., research consultant**
 - ❑ Two-year project funded by Greenwall Foundation and Jacob and Valeria Langeloth Foundation**
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Inclusion Criteria

- ☐ **Stroke or TBI as primary diagnosis**
 - ☐ **Discharged from hospital or sub-acute rehab facility within prior 1 to 2 weeks**
 - ☐ **“Family caregiver” broadly construed**
 - **Power of attorney, health care proxy**
 - ☐ **Caregiver aged 18+, English speaker**
 - ☐ **Receiving services from one of three metro NYC home health care agencies**
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Research Questions

- ☐ How are decisions to end formal home care made?
 - ☐ How and when are these decisions communicated to patients and families?
 - ☐ What happens to families and patients after formal home care ends?
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Research Methodology

- ☐ Interviews with 100 caregivers as soon as possible after home care starts, when it ends, and six and nine months later
 - ☐ Focus groups with clinicians (nurses, social workers, therapists) from CHHAs
 - ☐ Focus groups with home care aides
 - ☐ Longer follow-up interviews after final survey interview to obtain more in-depth information
 - ☐ Review of administrative data on service units
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Findings from the Study

- ❑ Difficult to do this research:
 - IRB review complicated by HIPPA; caregivers not part of an identified group; overwhelmed by care; not available for follow-up
 - ❑ Nevertheless, sample included diversity in income, race/ethnicity, location
 - ❑ About a third on Medicaid
 - ❑ Caregivers mostly females in their 50s
 - ❑ About 20% had quit work to do caregiving
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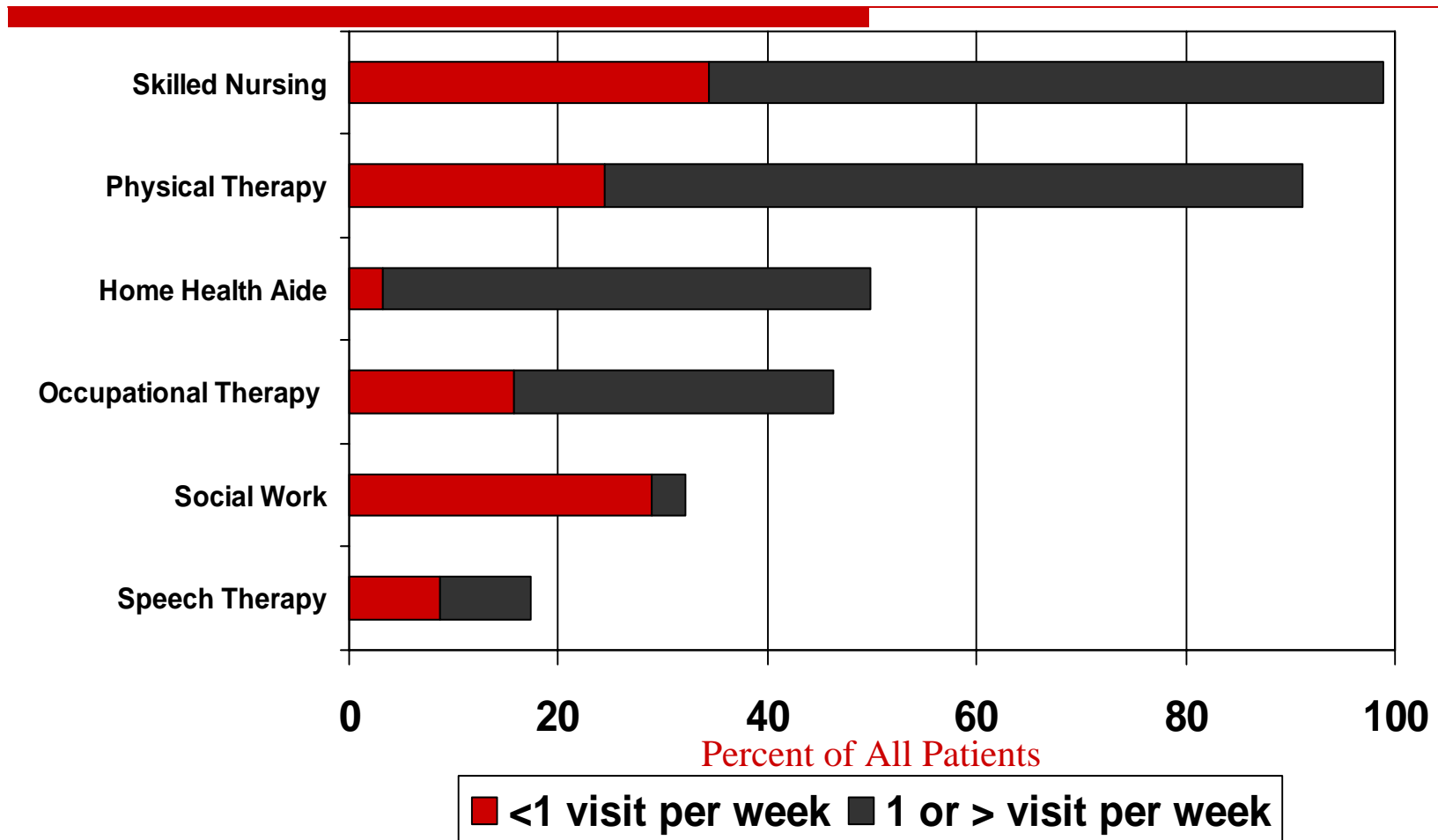
Stroke/TBI event triggers many decisions: family involvement influences all of them

- ☐ **Eligibility (who gets into home care)**
 - ☐ **Amount of service**
 - ☐ **Length of service (when home care ends)**
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Findings from the Study

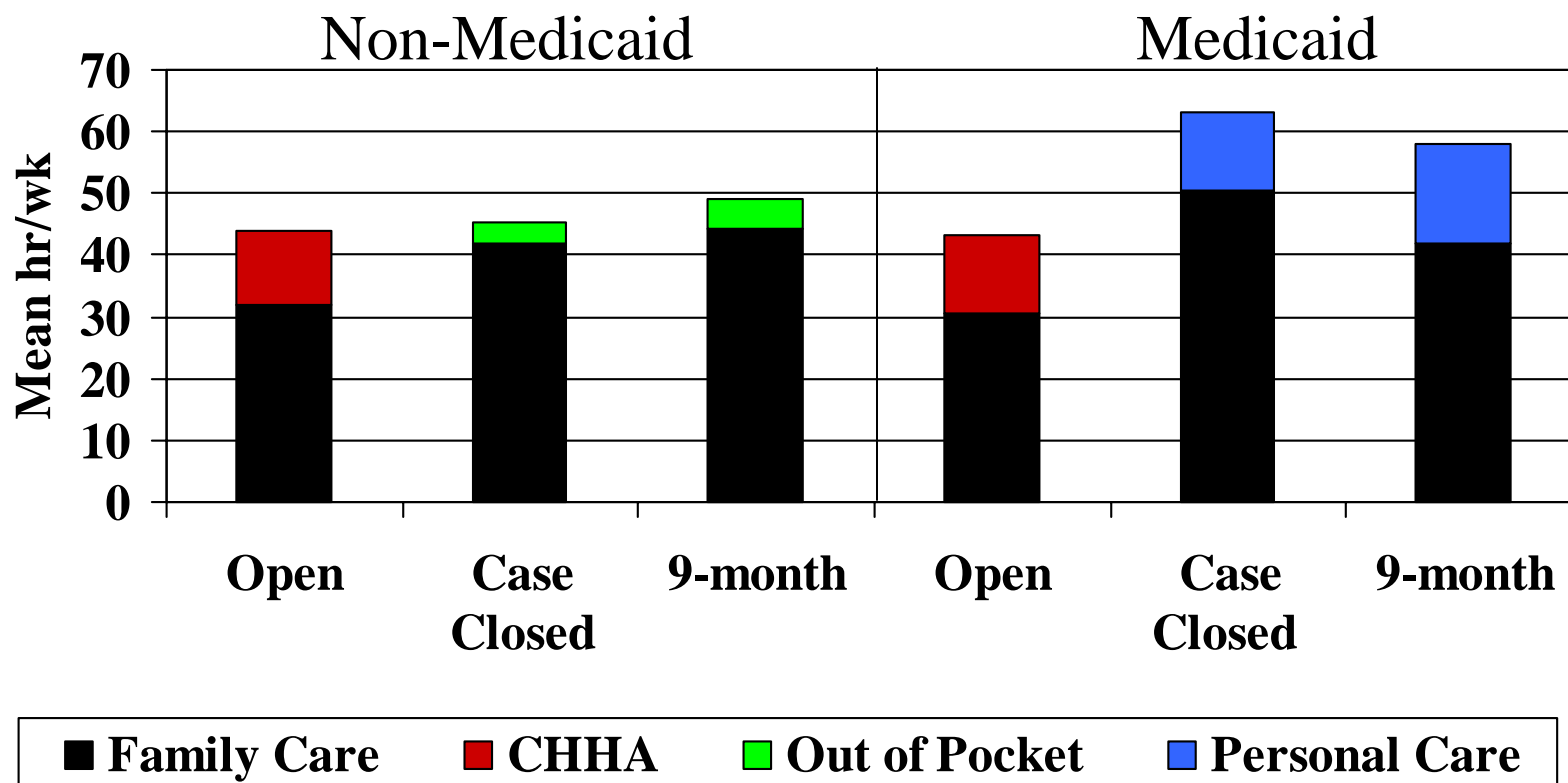
- ☐ Cases open a median of 59 days for patients on Medicaid, and 36 days for patients on Medicare or private insurance
 - ☐ Most common services are skilled nursing and PT; home health aide and OT are next
 - ☐ Caregivers provide 3/4 of the caregiving hours even while there is formal care
 - ☐ Mobility status and insurance affect services
 - ☐ Caregivers report significant burden at all stages
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Figure 1. CHHA Services by Type and Frequency



Source: CHHA Administrative Data, $n=97$

Figure 2. Paid and Family Care by Insurance Status



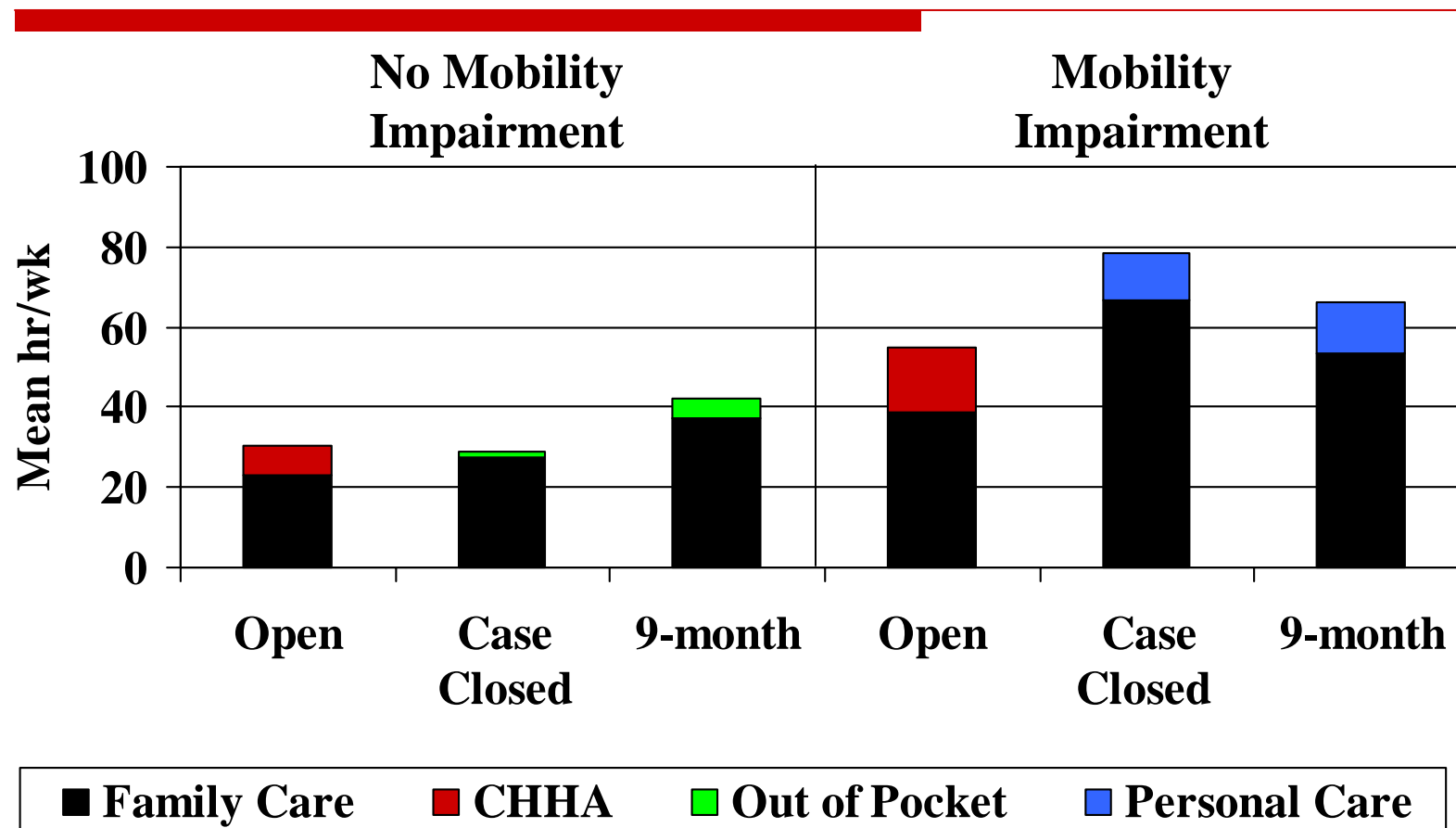
Source: Family Caregiver Interview.

Open, n=39

Closed, n=56

9-month, n=59

Figure 3. Paid and Family Care by Patient Mobility Status



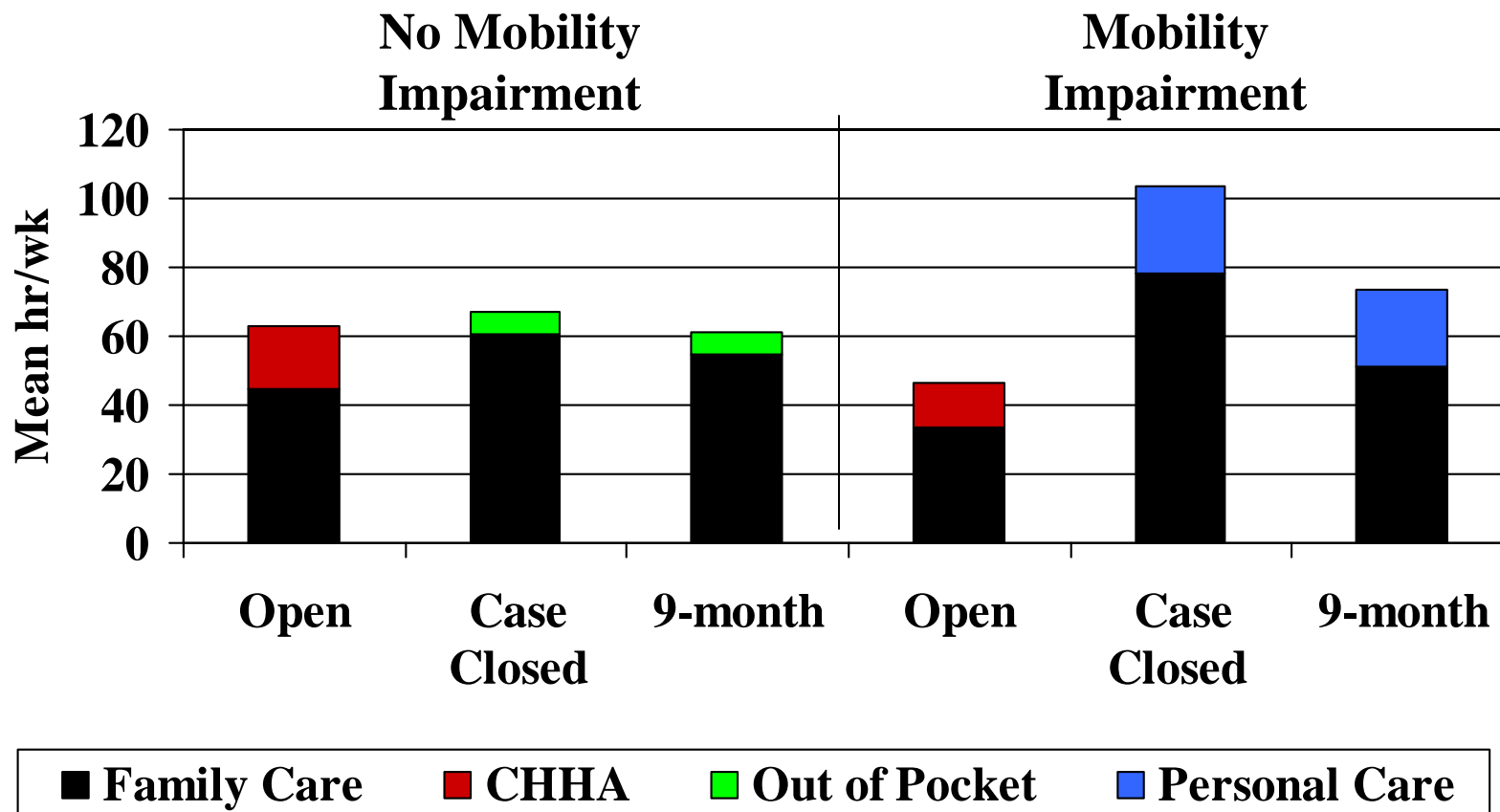
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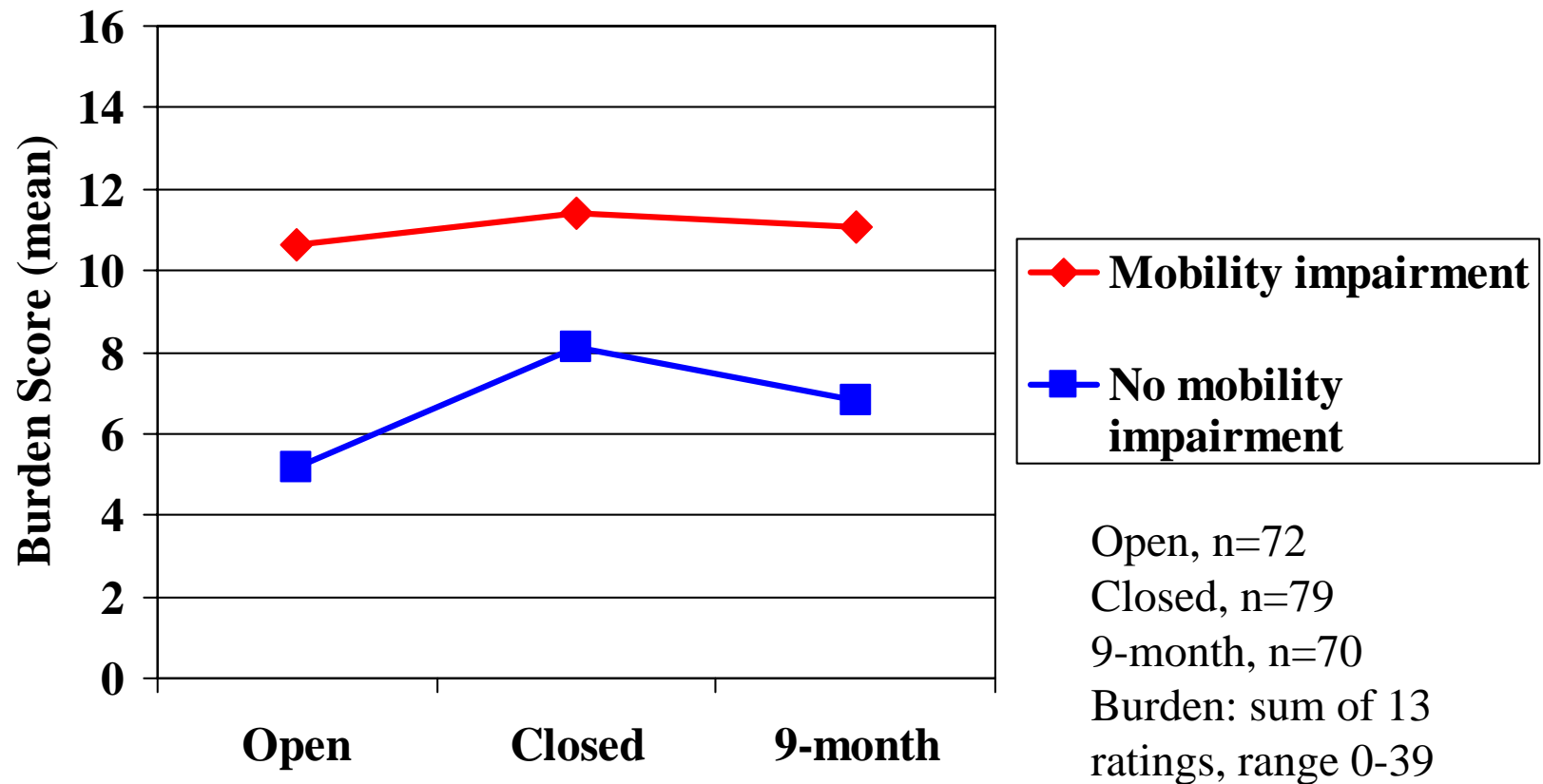
Figure 4. Paid and Family Care by Insurance Status for Patients with Mobility Impairment



Source: Family Caregiver Interview.

Open, n=39 Closed, n=56 9-month, n=59

Figure 5. Caregiver Burden by Patient Mobility Status



Staff face barriers in efforts to prepare families to address ongoing care needs

- ☐ **Limited time and visits; families not always home**
 - ☐ **Nurses focus on teaching families to perform some skilled care tasks**
 - ☐ **Nurses rarely mention training for personal care tasks, like bathing; PTs try to teach these skills when they can**
 - ☐ **Other teaching is selective**
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Being told is not the same as knowing

- ❑ Nurses emphasize that service is short-term; families may “know” but not be prepared**
 - ❑ Families are often grieving, coming to terms with major changes in patient’s condition and their own lifestyle**
 - ❑ Caregivers do not think of their own needs**
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The end of formal home care adds challenges to caregivers

- ☐ About half not told how long they could expect to have service and were not ready for case closing**
 - ☐ Even fewer met with agency to discuss the closing**
 - ☐ Less than a third consulted others for information or guidance**
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Few families receive social work services

- ❑ Social workers brought in mainly to resolve problems with discharge.
 - ❑ Social worker visits are limited.
 - ❑ Other professionals reluctant to authorize—some think they do what social worker does (nurse) or that only poor people need social workers (doctor).
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Conclusions

- ☐ Transition from formal home care is a difficult and anxious time for caregivers.
 - ☐ Families have inadequate information about structure of home care services, benefits, and avenues for assistance in community.
 - ☐ Clinicians are torn between acting as gatekeepers for resources/pressure to discharge and professional responsibilities to individual patients.
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The family caregiver in the middle

- ☐ Patient is the beneficiary and the client.
 - ☐ Family has no official or quasi-official status with the home care agency.
 - ☐ But home care services depend on family's labor and willingness/ability to provide care.
 - ☐ Regulations and practice should not assume or coerce family care; but when it is provided, it should be supported and valued.
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Implications for Policy and Practice

- ☐ Home- and community-based services and disease management programs depend on family caregivers as providers and monitors of care
 - ☐ Family caregiver assessment and support must be built into these programs
 - ☐ Financial and other incentives are needed to ensure services for families; care management as usual will not include families without specific responsibility, accountability, and training.
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